Maine Newborn Hearing Program Advisory Board

Senator Inn & Conference Center, Augusta Maine Date: September 10, 2008 12:00 to 4:00

Members Present: Romy Spitz, Eileen Peterson, Karen Harrison, Karen Hopkins, Kristen Shorey, Louise Packness, Harriet Gray, Carrie Chojnowski, Cindy Brown, Annette Bowman, Deb Stroud, Lisa Sockabasin

Program Staff: Betsy Glencross, Amy Peaslee, Pattie Chasse

Interpreters: Mary Jane Grant, Tina Morrison

Members Absent: Brenda Medlin, Michelle Markie, Karen Perry

Moderator: Betsy Glencross

Scribes: Betsy Glencross, Amy Peaslee

Approval of minutes from: May 28, 2008, accepted.

I. MNHP Update: Betsy Glencross

- MNHP was awarded both of our grants for the next three years. We will be 100% federally funded. This will be discussed in more detail later in the meeting.
- MNHP Family Survey: 6750 surveys were sent out. Approx. 600 returned with due to address issues that we discovered was a problem with how we are getting address data. We received back over 1300 completed surveys. This will be discussed in more detail later in the meeting.
- Audiology:
 - o Jim Dean has been visiting some of the audiology facilities. We are working on updating our audiology facility information sheets but having some problems with responsiveness.
 - o We are working with Maine Academy of Audiologists (MAA) on a 2-day conference in Wells in October. Day 1 is designed for a small group (mostly our category A facilities) to get some of the latest info and have hands-on practice opportunity. Nationally recognized speaker will be working with this group and also presenting on the 2nd day. All members of the MAA will be invited to Day 1 on a first-come first-served basis. The dates are Oct 23-24. We are doing this in collaboration with the NH EHDI program and also working with the NH EHDI coordinator and audiology consultant on other possible collaborative opportunities. We will have a vendor table on the 2nd day of the conference and are willing to provide space for other Maine agencies to have their materials. Contact Betsy if interested.
 - o Our reporting data from audiologists is looking much better. At the March Advisory Board meeting, Betsy reported the preliminary 2007 reporting rate as 32%. Now it is 44%. The preliminary first quarter 2008 reporting rate is 54%!

- o We are having a ChildLINK (database) meeting on September 26th with Jim Dean in attendance to discuss a few issues with the audiology data and reporting process, in hopes of improving the quality of data we report to the CDC.
- Home Birth Screening: Ballard House (free-standing birth facility) closed in May. Betsy is working with another midwifery practice who is interested in providing this service. She just got approval from Toni to do a 'pilot program' with them to assist them with the financial aspects of running the screening equipment. She is working on getting a meeting set up to discuss this in more detail. There are also discussions with another midwifery practice about issues for homebirth families having access to hearing screening. Annette and Debbie added information about how hospital screenings might work for home births. Annette agreed to bring this subject to the Perinatal Nurse Managers meeting on Sept 19th and will provide feedback to the Advisory Board on what she learns.

Next Steps: Romy will send out to the Board a list for all abbreviations/acronyms used in

meetings.

Responsible Person: Romy Spitz

Time Frame: ASAP

II. Actions Items from Previous Meeting

• Subcommittee Updates

Specialty Provider

- ◆ Romy presented information about the database she created for the Specialty Provider List based on the work done by the subcommittee. Handouts with an example of what information would be available were handed out to those present.
- Romy requests that Board members review the handout in order to discuss any changes at the next meeting

Membership

- ♦ Kristen reports that there are still two open seats: 1. Parent of child who is deaf or hard of hearing. 2. Culturally Deaf
- There are a couple of potentially interested parents for the open seat
- No current leads on the culturally Deaf seat.

o Educational Materials

◆ Louise reported that no further work has been done on the "script" for birthing facilities since the last meeting.

o Survey and Rules

♦ No current work for these subcommittees

Legislative Updates

The data-sharing law that was passed during the last legislative session has now become effective. This allows Maine to share and receive newborn hearing data with the other New England states. The New England groups are working on the rules, logistics, and creating a database for sharing the data.

III. New Agenda Items:

• Meeting structure

O Louise mentioned that during the break, several Board members were discussing possible changes to the MNHP Advisory Board meeting structure. Louise offered to email the Board membership in order to elicit some ideas for possible changes, including the possibility of providing time before, during or after the meetings for sub-committees to do their work while everyone is together.

Next Steps: Louise to email the board about meeting structure and Board membership

agreed to provide input

Responsible Person: Louise Packness

Time Frame: ASAP

• Advisory Board Elections

O Romy's term as Chairperson has ended. Louise will now assume this position. Carrie Chojnowski was elected as co-chairperson.

• Family Survey

- o Betsy reported that just prior to the meeting, she had received a 25 page draft report from the Survey Evaluator. She has not had time to really review the report but wanted to share some preliminary information.
- o As previously mentioned during the meeting, 6750 surveys were mailed out to mothers of babies born in the last 6 months of 2007. Approximately 600 were returned due to address issues. Over 1300 completed surveys were received.
- o We received completed surveys from families whose children had normal hearing loss, referred on hearing screen but subsequently passed follow-up and those whose child was diagnosed with hearing loss in comparable numbers to the data we have for our population. (approx 2-3% refer rate and approx 3 in 1000 diagnosed with hearing loss)
- o One clear area identified by families is the need for more information about hearing screening, especially prior to the screening being performed.
- o The survey report will be mailed out to the Board members as soon as it is available and will be discussed at an upcoming Board meeting in further depth.

Training Video for Birth Facility screening

- O Betsy mentioned that she recently received a DVD from NCHAM (National Center for Hearing Assessment and Management) that was developed for training staff who perform newborn hearing screenings.
- o The DVD also provides some possible scripts for nursing staff to use in providing information about the screening and results to families and health care providers.
- o The DVD is available to MNHP for a minimal cost and Betsy offered to share the DVD to anyone interested and also suggested that Board members could view the video online at www.infanthearing.org
- o Both Annette Bowman and Deb Stroud voiced support for training for nursing staff. Annette offered to provide information on this to the Maine Perinatal Nurse Management group at their meeting on September 19th.

• MNHP Presentation Subcommittee

- o Louise recommended that the MNHP Advisory Board submit a proposal to present information about the MNHP and the Board's encouragement of speech language pathologists to work with young children/infants with hearing loss at the Spring conference of the Maine Speech and Language Association.
- o Board members agreed this was a good idea.
- o Board members who agreed to participate on developing this presentation are: Louise Packness, Cindy Brown, Carrie Chojnowski, Kristen Shorey, Eileen Peterson, Romy Spitz and Karen Hopkins.
- o Louise will organize a meeting for this group.

New HRSA and CDC-EHDI Grants

- o As Betsy previously mentioned, MNHP was awarded two 3-year grants. This allows the Program to be 100% federally funded.
- o A handout with summary information on each grant was provided in the meeting packets.
- o HRSA (Health Resources & Services Administration, Maternal & Child Health Bureau) Grant
 - ◆ Funding period is 9-1-08 to 8-31-2011
 - ◆ Focus of the grant is "Lost to Documentation" and other follow-up to newborn hearing screening issues.
 - ◆ Funds pay for contracts for audiology consultant, parent consultant, epidemiologist, evaluation; educational materials; training; some travel expenses
- o CDC-EHDI (Centers for Disease Control-Early Hearing Detection and Intervention)
 - ♦ Funding period is 7-01-2008 to 6-30-2011
 - ♦ Focus of the grant is to meet the "1-3-6 Goals" established by EHDI (all babies will be screened for hearing loss by 1 month of age, those that refer on the screening will be seen for follow-up with an audiologist by 3 months of age, and those diagnosed with hearing loss will receive appropriate early intervention services by 6 months of age) and to track the data associated with those goals
 - Funds for this grant are used primarily for operational expenses: NBH Coordinator's salary; office space, supplies, equipment, tracking database, some travel expenses.
- o Betsy asked the Board to provide the Program with suggestions and input for what they feel the Program should do over the next 3 years.

• 2009 EHDI Conference

- o March 9 & 10th in Dallas, TX
- o MNHP will not be allowed to pay for a Board member to attend. Only Program/Contractual staff will be allowed to go using our grant funds.
- o Betsy encouraged other members to attend if they are able.

• MNHP Advisory Board Orientation

- o Romy Spitz suggested that we provide an orientation program for newer Board members.
- o The Board agreed this was a good idea.

- o Romy and Karen Hopkins volunteered to help Betsy in planning and presenting the orientation.
- o Betsy will contact the Senator to see if we can have the meeting space an hour earlier for the next meeting. [Note: The Senator is available, but after discussing items further with Romy and Karen, we have decided that the hour prior to our next meeting, Romy, Karen, and Betsy will use this time for planning the program.]

• 2009 Meeting Dates

- o The following MNHP Advisory Board meeting dates were set for 2009: Wednesday, February 11th; Friday, May 1st; Wednesday, September 23rd; and Friday, December 4th.
- o Betsy will confirm these dates with the Senator and the interpreting agency.

IV. Networking/Sharing Info

- Karen Hopkins announced a conference for Early Intervention providers will be held at Boston Children's Hospital at Waltham on October 17th. The conference is "Art and Science of Home Visits" with Arlene Stredler Brown.
- In conjunction with this, on October 16th, there is a Roundtable discussion scheduled to discuss Early Intervention Programs and Hearing Screening Programs to discuss strategies, challenges and solutions for working together. Betsy, Karen Hopkins and Debra Hannigan from Child Development Services are planning on attending.

V. Plan for Next Meeting

- December 5th, 12-4PM at the Senator Inn & Conference Center
- Janet Farrell, Massachusetts EHDI Coordinator and our NCHAM Support person has been asked to attend and present information and facilitate a discussion on early intervention and meeting the "6" goal established by EHDI